500 PROTEST GOV'T INACTION

Nearly 500 people marched down Yonge Street Friday night, March 25th, to protest the Federal Government’s failure to streamline testing of new AIDS drugs in Canada.

The rally was organized by AIDS ACTION NOW! in response to a proposed study of aerosolized pentamidine in which half the participants will be given a placebo (non-effective substance) instead of the real drug. (see Placebo Roulette on page 3)

“The proposed experiment is evil,” said person with AIDS Bill Greenways, addressing protesters at the rally. “In its proposed form it will undoubtedly cause unnecessary suffering and death.”

Greenways pointed out that the pentamidine treatment is already available on compassionate grounds in the United States.

“It’s taken two years for the Federal Centre for AIDS to get any drug testing going in Canada,” says AAN! spokesperson Tim McCaskell, “and now the first study that’s proposed is ethically flawed.” Despite rainy weather, the march ended with a candlelight vigil in front of Toronto General Hospital, one of seven Canadian hospitals participating in the pentamidine study. Says Gary Kinsman of the Public Action Committee, “We were really pleased with the turn-out. I think we’ve forced the powers-that-be to take note of us and to see that our community is upset by what they’re doing.”

Members of Lesbian and Gay Youth Toronto at AIDS ACTION NOW! candlelight vigil at Toronto General Hospital March 25th.

A Tale of Major Betrayal

This is a tale of betrayal with moments of heroism and moments of the sort of comedy we could all do without.

Toronto’s earliest diagnosis of what we now know as AIDS, according to one source, came about in June, 1980. John Sewell was mayor, George Hislop was raising funds for his run for city council later in the year and the Toronto School Board was debating whether or not to liaise with the gay/lesbian community. Anita Bryant (remember her?) was divorcing what’s-his-name. The diagnosis of Kaposi’s Sarcoma lesions on the face of a gay man made no headlines.

Six years passed. AIDS cases multiplied. The government did piss-all about finding drugs to combat the new syndrome. But on 6 October 1986, the minister of National Health and Welfare made a bold pledge. (Here comes the moment of heroism.) “The policy of the Health Protection Branch,” he announced, “is to seek out, encourage the availability, and facilitate the use of experimental drugs in Canada.” Furthermore, he added, “everything possible” — those are his words — “everything possible will be done by the Health Protection Branch to facilitate the whole process.”

Dear Jake Epp, we might have written, since Epp was (and is) the Minister in question — what a fabulous promise! What leadership this shows! What hope you give to Canadians with AIDS and ARC, to people who test positive for the HIV virus. “Everything possible,” and this in a strong policy statement to a Standing Committee in the House of Commons.

continues on page 2
Fisons Pentamidine Study

The Fisons aerosolized pentamidine study, which has been opposed by AAN!, because of the use of placebos, is indefinitely postponed. On March 16, Fisons held a meeting in Toronto with some of the principal investigators of the study and representatives of the HIV Primary Care Physicians Group, the Health Protection Branch and the Federal Centre for AIDS to discuss the problems with the study. No agreement was reached on a way to eliminate the use of placebos.

After the meeting, the primary care group and the investigators agreed to ask Dr. Arnold Johnson of McMaster University to form an independent opinion as to the design and ethics of the protocol, which would be accepted by both groups. No report has been issued and the study remains in limbo. Even after Dr. Johnson’s report, the protocol would still need to be approved by the ethics committee at each participating hospital. It was hoped that Fisons might propose an additional study of aerosolized pentamidine in people after multiple episodes of PCP that did not use a placebo but this hasn’t happened.

AIDS and Syphilis

On March 26, 1988 Dr. Stephen Caiazzo of New York City addressed a symposium on “AIDS and Syphilis” sponsored by the Community Initiative For AIDS Research (CIFAR). Dr. Caiazzo presented his view that the organisms that cause syphilis are the primary causative factor in AIDS. He outlined his current treatment practices involving the administration of large doses of penicillin to AIDS/ARC patients and discussed his promising results to date. Two recent papers published by Dr. Caiazzo on his work and a cassette of his presentation are available from CIFAR by writing to CIFAR, 72 Major Street, Toronto, Ontario MSS 2L1 or by phoning 960-2471. A donation of $10.00 is requested to cover the costs of reproduction.

AIDS Action News!

because of withheld treatment. Immoral, indecent and scurrilous.

The scenario is grim. To the Ministry of Health, our lives count about as much as those of laboratory mice. But it is not hopeless. If the PWA’s from Vancouver could get AZT for PWA’s across the country, gay men and our friends can act together to get more drugs available to those who need them.

What can you do?

If you are HIV positive, you should certainly take advantage of the new Resource Centre at the AIDS Committee of Toronto (926-0063) or the phone-line of AIDS ACTION NOW! (591-8489) to inform yourself about the most promising drugs. Three very reliable newsletters are now being published to keep gay men up-to-date. Consult them! Since Epp’s ministry has not informed the medical community about these drugs, you cannot rely on your doctor to know about them. But you can educate him/her and stimulate his/her interest in pressuring Epp to make these drugs available.

You may want to let the specialists know you’re not going to engage in unethical testing and insist that if you help them in conducting a test, you want their commitment to making their trial drugs available to ALL who may benefit from them, not just a select elite.

You may want to seek out ways by which you can get some of these drugs yourself, either because they are already available here though not widely recognized as AIDS drugs, or import them from the U.S.

Most importantly, you can let your voice be heard by the politicians and the press that we, as a community, are pined off by the major betrayal of Jake Epp’s career—his failure to keep that promise he made 560 days ago. His betrayal has wasted the lives of our community. If this does not quite amount to genocide—as some argue it does—it at least amounts to malicious indifference. Perhaps murder.
### The Pentamidine Project

To make aerosolized pentamidine (AP) immediately available for those who wish to use it under the supervision of their physicians, AIDS ACTION NOW! has started the Pentamidine Project. Here's how it works. Physician Information Packages about the indications and use of AP were prepared and distributed to doctors who care for PWA's. A phone line (591-8489) was established and publicized. By calling this number, people get information about the drug, where to get it in Buffalo, how much it costs, which doctors will supervise its use and then are sent a Patient Information Package. We help co-ordinate funding when needed via AIDS Committee of Toronto and the Toronto PWA Foundation and have organized a car pool for going to Buffalo. To date, 130 information packages have been sent out and 20 calls received on the phone line. Three people have started to use AP. All this for a cost of about $300 — less than the cost of half a day in hospital!

One phone line answerer says the work is challenging. "It's not just short calls for information. People want to talk about all the problems of living with AIDS. And they seem grateful that we're taking the initiative in giving information about the latest in treatments available."

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### Placebo Roulette

AIDS ACTION NOW! wants to have promising AIDS drugs made available to HIV-positive people who would like to use them on the advice of their physician.

To date only one drug has been approved in Canada for the treatment of AIDS, and that is AZT. This only came about because the Vancouver PWA Coalition forced the issue on the government in a face-to-face meeting with the Minister of Health, Jake Epp. In the United States, more than a dozen drugs are undergoing trials.

Canada's Health Protection Branch and Federal Centre for AIDS have taken no initiatives in the testing of AIDS drugs. The strategy, it seems, is to leave testing up to the multinational pharmaceutical companies who appear not to be interested in Canada because the market is too small.

Late last fall, Michael Lynch, the chairperson of AIDS ACTION NOW!, wrote an article for The Globe and Mail and appeared on television to protest the fact that aerosolized pentamidine, an anti-PCP drug showing great promise in the U.S., was not available in Canada.

The response of the federal government and of some hospitals in Toronto, Montreal and Vancouver was to propose a six-month, double-blind placebo trial for the drug. This would involve 300 individuals who have had one bout of PCP, half of whom would be given the drug, and half would not. Neither the doctors nor the participants would know who got the drug and who merely got a placebo. The trial would take six months.

Given the present mortality rate for people who contract PCP a second time, some of the 150 individuals who would not get the drug would likely die.

AIDS ACTION NOW! is opposed to these trials for two reasons: First, it is unethical to use double-blind placebo drug trials with people who are critically ill, especially in order to release a drug that has been shown to be effective.

Secondly, while AIDS ACTION NOW! does not promote specific treatments, it does believe that individuals in life-threatening circumstances should have the right to choose drugs that they and their physicians think will be beneficial. AIDS ACTION NOW! realizes that the treatment of AIDS raises serious ethical issues. It is not sufficient, however, for the medical establishment to retreat behind the "standard procedures" of double-blind placebo trials as a way of sweeping these issues under the rug. Standard procedures in situations that are not standard can be unethical.

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### Public & Media Relations Committee

Function: Ensures that the issues raised by AIDS ACTION NOW! receive wide public attention by alerting the media to the activities and protests organized by the Public Action Committee as well as to related events. Monitors media coverage of the issues and events. Produces this occasional newsletter.

Meetings: No set schedule. Call.

Contact: George Smith, 362-2877

### Fund Raising Committee

Function: Ensures that AIDS ACTION NOW! has sufficient funds to carry on its protests, lobbying and public information activities. Raised $1,415 at the February 4th rally at Jarvis Collegiate and $892 at the March 25th rally at the 519 Community Centre.

Meetings: No set schedule. Call.

Contact: James McPhee, 960-2471

### Public Action Committee

Function: Organizes public activities and protests to bring public attention to the demands of AIDS ACTION NOW! This was the committee that put together the successful rally/demonstration/vigil on March 25. (It's also looking for volunteers willing to participate in civil disobedience actions.)

Meetings: First and third Tuesday of every month at 8 pm at the 519.

Contact: Gary Kinsman, 534-0613
Help Wanted

If you are interested in working on any of the following positions, leave your name and number on the AAN! phoneline 591-8489.

Membership Secretary

Several hundred volunteers have filed their names with AIDS ACTION NOW! and we need someone to co-ordinate ways to develop this volunteer base. Interested? Leave your name and number.

Networker

ACTUP in New York, ACTUP in Los Angeles, PWA Coalition in Vancouver. AIDS ACTION NOW! should be in regular touch with these and other AIDS action groups. Could you devote 2—3 hours a week as our "co-ordinating secretary." If so, leave your name and number.

Fund Raiser

AIDS ACTION NOW! needs money. Got any ideas? Do you have time to co-ordinate people and resources? If so, we'd like to meet you.

Research & Development Committee

Function: Identifies problems related to AIDS care in Toronto and the goals of AIDS ACTION NOW! and develops strategies to solve them. For example, it organized the Pentamidine Project to help people who have had PCP to get aerosolized pentamidine which has not been available in Canada through normal medical channels.

Meetings: No set schedule. Call

Contact: Denis Conway, 971-8024

U.S Presidential Commission Agrees With AAN! Policy on Placebos

(story credit: GUARDIAN, New York City)

Admiral James Watkins, chairman of the Presidential AIDS Commission, surprised AIDS activists Feb. 24 by issuing a set of remarkably progressive recommendations on tasks to be undertaken by the U.S. federal government to fight the disease.

Watkin's plan, the first of two sets of proposals to be issued by the commission, would dramatically increase federal funding for AIDS patient care, drug research and drug addiction treatment programs, to the tune of an additional $2 billion a year.

The recommendations encompass many AIDS activists' most radical proposals on the development and distribution of new AIDS drugs:

• immediately increasing access to clinical trials for women, minorities and IV drug users, groups that are almost universally denied access to new AIDS therapies;
• tripling the number of full-time employees working on federal clinical drug trials;
• greatly expediting clinical trials and Food and Drug Administration (FDA) approval mechanisms for new drugs;
• removing placebos in clinical trials wherever possible, since untreated AIDS is inevitably fatal;
• mandating a special FDA approval process for medical foods such as AL-721, thought to be effective in fighting AIDS but as yet unapproved for treatment in the States;

• establishing a federally-funded, central database on new AIDS drugs and research, available both to health workers and to the public;
• providing substantial funding for community-based clinical trials which provide otherwise expensive or unobtainable experimental drugs to people with AIDS and HIV infection.

Lobbying Committee

Function: Lobbies government and opposition politicians and government officials at the federal, provincial and municipal levels to gain support for the demands of AIDS ACTION NOW!

Meetings:
No set schedule. Call

Contact: Roger Spalding, 323-3425

AAN! Financial Statement

Income:
Jarvis Street Meeting .................................................. $1,415.00
March/Demo ................................................................. .892.00
Bank Interest ............................................................... .3.14
Total ................................................................. $2,310.14

Expenses:
Administration (letterhead, phone, answering machine).................. $242.14
Jarvis Collegiate Meeting ................................................ 229.89
March/Demo ................................................................. .464.79
Total ................................................................. $936.82

Balance ............................................................. $1,373.32
Lesbian and Gay Pride Day is an occasion to remind ourselves of our right to exist and an opportunity to celebrate our difference. Our coming out and our feeling good about ourselves are always restrained, however, by society’s rejection of our difference. Homophobia hurts us all, lesbian, gay, straight, or bisexual.

The AIDS crisis has given an element of our society an opportunity to voice and to act on their homophobia. The AIDS struggle — the fight to give not only people living with AIDS (PLWA), but all those who are HIV positive, proper care and medical treatment — cannot be separated from the cause of gay liberation.

Homophobia is not merely the bigotry of a Jerry Falwell or a William Vander Zalm. It is also politicians who fail to provide leadership in this crisis because it is “only fags who are dying.” Or bureaucrats who shuffle their papers and collect their salaries without the slightest concern for urgency because “hemos have only themselves to blame.”

Homophobia is the exclusion of gay men with AIDS from proper treatment and medical care at all levels and in all jurisdictions of the health care system. AIDS ACTION NOW! is committed to fighting this kind of institutionalized homophobia. For this reason, AIDS ACTION NOW! is happy to be a part of Pride Day.

On June 8, three weeks after our protest march through downtown Toronto demanding the government step up its efforts against AIDS, federal Minister of Health Jake Epp announced Ottawa would grant $129 million in this area over the next five years.

The federal government’s new $129 million plan includes:

- $48 million for education, including a national AIDS awareness campaign.
- $35 million for scientific research, including work on an AIDS vaccine and new drug treatments.
- $20 million for AIDS prevention and special care for those who are ill, to be funnelled through private organizations such as support groups and hospices.
- $10 million to train health workers, develop new ways to care for AIDS patients and start AIDS training in the workplace.
- $10 million to run the program and develop AIDS policies.
- $6 million for international AIDS efforts.

AIDS ACTION NOW! believes that the amount allocated to treatments should be doubled. The policy of a cure or nothing, and of ineffective, soft-sell education programs have prevented more money from being set aside for developing treatments more promising than a cure.

On June 13 and 14, not a week after the federal government’s announcement, The Toronto Star published a poll it commissioned from Goldfarb Consultants on Ontarians’ attitudes towards AIDS. One of the few positive responses to this survey was that 93% favoured the
inclusion of specific descriptions of safer sex and the use of condoms in school courses.

A number of the Goldfarb questions, however, continued to treat AIDS as a gay disease. For example the survey asked, “As a result of AIDS do you think Canadians will be more willing or less willing to accept homosexuality?” (74% said less willing.) Similarly, it asked, “How concerned would you be about picking up AIDS from intimate contact with a homosexual?” (11% of respondents were “very concerned”).

Another question elicited a response from 65% of the 800 surveyed, who “foresee a drop in homosexual practices in the years ahead” — as if homosexual practices cause AIDS; forgetting, of course, the relatively high rate of anal intercourse among heterosexuals. The way these questions are worded and the publication of their results in a major newspaper no doubt continues to contribute to the homophobic treatment of PLWA’s.

Aside from The Toronto Star poll, however, there are some hopeful signs: both the Federal and Ontario Human Rights Commissions have taken some initiatives to protect the civil liberties of PLWA’s.

The Ontario Human Rights Commission has said that it does not consider AIDS to be significantly different from any other handicap in the application of the Human Rights Code. This means that in an employment setting, persons with AIDS, ARC or the HIV virus (as well as those who are suspected of having these conditions) cannot be treated differently from any other employees, except for those narrow circumstances involving risk to others. Even in such circumstances, an employer will not be entitled to limit a person’s right to work in a particular setting without showing that reasonable accommodation (such as the use of protective measures) could not be made.

Last month the federal Human Rights Commission announced a similar policy.

Notwithstanding the Human Rights Code of both Canada and Ontario, there are still many serious situations where PLWA’s are being discriminated against, essentially because the disease is seen as a “gay plague.” AIDS ACTION NOW! believes that there is an urgent need for treatments for both HIV infection and homophobia — two diseases: one medical, one social — which have a crippling effect on our society.

G.S./B.C.

LOBBYING COMMITTEE MEETING

People interested in helping with lobbying at the provincial and federal levels are invited to attend a meeting of the Lobbying Committee

WHEN: Wednesday, June 29th, at 7:30 P.M.

WHERE: ACT Boardroom, 464 Yonge St., Suite 201

Treatment AIDS #1

Information on treatments for PLWA’s and those who are HIV positive

Get in touch with AIDS ACTION NOW! if you would like a copy
(416) 591-8489

AIDS: CANADA’S TOP SCIENTISTS AND ACADEMICS DEMAND ACTION NOW!

From “AIDS: A PERSPECTIVE FOR CANADIANS,” by The Royal Society of Canada, Canada’s most distinguished group of scientists and scholars. It contains more than 50 recommendations on dealing with AIDS in Canada.

On Research:

• More public spending on AIDS research: a minimum of $35 million a year. A mere $4.26 million was allocated by governments and their agencies for 1987/88, down from $4.65 million in 1986/87.

• More clinical research, more drug trials, more epidemiological studies, more scientists involved in AIDS research.

On Health Care:

• An end to the current system of ad hoc health care for people living with AIDS. Few Hospitals have clear admission and treatment policies. On any given day there are 100 to 150 AIDS patients in Canadian hospitals and only 18 beds officially assigned to them in the entire country.

• A network of “dedicated” health care facilities for people living with AIDS, funded with new resources, not with money taken from existing programs:
  - special in-patient and out-patient facilities
  - screening and counseling clinics
  - home care, extended care and terminal care facilities
  - university-affiliated AIDS centres to coordinate education, research and patient care.
Better training and counseling of health care staff working with people living with AIDS.

- the risk for health care workers becoming infected at work is so slight that it would be "unethical" for them to refuse to care for people living with AIDS.

On Social Support

- More counseling and psycho-social support for people living with AIDS, as well as for their friends and families.
  - "the effects of AIDS are social, psychological and economic as well as physical."

- Improved social benefits including financial support and subsidized housing for people living with AIDS and their dependents.

On Legal Issues

- Enforced legal sanctions against the release of confidential health information, including the results of HIV tests.
  - any breach of confidentiality about an individual's test for HIV "may well have devastating effect."

- The amendment of all human rights legislation to prohibit discrimination based on HIV infection, perceived HIV infection, sexual orientation and perceived sexual orientation.

Excerpts prepared by Mark Gerson

AAN! Pentamidine Project under way with two participants using nebulizers under the supervision of Dr. Wayne Boone. Photo by Chuck Grochmal

Pentamidine Update

Over thirty individuals are currently receiving aerosolized pentamidine as a prophylactic treatment to halt the occurrence of Pneumocystis carinii pneumonia (PCP), under the project set up by AIDS ACTION NOW!. The atomizers, which convert pentamidine into a mist, are running non-stop on Thursdays, when the clinic is in full operation.

Jeff Kirby


AIDS activists in the USA have hailed the final report to President Reagan from the Presidential Commission on the Human Immunodeficiency Virus epidemic. The report contained 583 recommendations. The report recommends the strengthening of measures to prevent discrimination against PLWA’s. It also acknowledges gay families and calls for measures to deal with increased violence against gays. Admiral James Watkins, chairman of the Commission, stressed the need for new laws to protect confidentiality.

The report also called for greater state and federal innovative methods of financing health care, a shift in the focus of collecting statistical data to "the entire range of the HIV epidemic," and the implementation of a comprehensive health education system.

US AIDS activists are concerned, however, over two of the report's recommendations; one that would put in place a partner notification system, and another that would institute laws criminalizing the knowing transmission of AIDS. It is generally believed that partner notification systems act as a disincentive to high-risk individuals to take the HIV antibody test. Similarly, it would be difficult to prosecute a person for knowingly transmitting AIDS if s/he did not know what her/his HIV status was.

Of particular interest to AIDS ACTION NOW!, the report included recommendations calling for 120 new full-time employees for research, 50 to work on the approval of new drugs/treatments, and 73 at the National Institute of Allergies and Infectious Diseases. It also stressed the important need for scientific researchers to work with community-based research initiatives.

George Smith
OTTAWA, May 25, 1988. Members of AIDS ACTION NOW! in front of the Peace Tower protest government inaction in making test drugs available by taking four of a dozen treatments that are available elsewhere in the world. From left to right, Bill Greenway, PLWA, is inhaling aerosolized pentamidine by using a misting nebuliser; Michael Lynch, HIV positive and Chair of AANI, is taking naltrexone; James Thomas, PLWA, is taking dextrane sulfate; and Chuck Grochmal (not shown here), PLWA, is taking AL-721.

PHOTO: Philip Hannan.

TORONTO, June 19, 1988. “Their summit ignores AIDS — Silence equals death!” Such was the chanting that could be heard from the AAN! contingent that joined the Popular Summit demonstration in Queen’s Park. PHOTO: Celest Natale.

TORONTO, May 17, 1988. A demonstration organised by AAN! and supported by the Canadian AIDS Society (the umbrella organization of Canadian AIDS groups) was staged during the national AIDS conference. Some 300 protesters watched as federal Health and Welfare minister Jake Epp burned in effigy. PHOTO: Celest Natale.
AAN! at Toronto's Popular Summit

A boisterous AIDS ACTION NOW! contingent joined in a large protest against the meeting in Toronto of the leaders of the seven major western industrial nations. Joining groups such as the Toronto Anti-Intervention Coalition, various labour groups, groups against free trade, apartheid groups, and the Canadian Organization for the Rights of Prostitutes (CORP), we protested against the fact that AIDS was among many important issues missing from the leaders' agenda.

The leaders' summit virtually took over Toronto for the period of their meeting, June 19-21. Police sweeps of prostitutes, constant motorcades taking over streets and disrupting both traffic and pedestrians, as well as the curtailing of our rights to assembly and free speech were just the outward signs of a security blanket that has been estimated to have cost Canada close to $20 million. Even compared to the $129 million announced to be spent on AIDS over the next five years, $20 million is a large amount to spend on seven people for four days!

A spokesperson for CORP talked about the relationship between what is happening around AIDS and gay men and AIDS and hookers. The health crisis is being used against both groups in similar ways. She also explained that the federal government's Bill C-61 will be one of a long line of laws that will keep people from engaging in prostitution -- something that is not illegal in this country. A spokesperson from the Ontario Coalition for Abortion Clinics then spoke and explained what she saw as the similarities between our two struggles -- the fight to have control over our sexualities and the right to the health care that a person chooses -- not one that is imposed by hospital boards or governments.

Anthony Mohamed, spokesperson for Lesbian & Gay Youth Toronto, then spoke about AIDS and racism and asked why there were not more people present when almost 20,000 were expected for Pride Day. He also wanted to know why these countries have not done anything to help fight the AIDS crisis in Africa where AIDS is much more widespread than here. He summed up his remarks with the question, "Why are our fundamental rights being taken away just because the seven leaders of the Free World are getting together?"

In Canada, the federal government continues to refuse to release promising experimental AIDS treatments that have been shown to be effective elsewhere and federal minister of health Jake Epp continues to refer to AIDS as a "lifestyle problem."

In the USA, the Reagan regime is so blinded by homophobia and racism that it is totally unable to respond to the crisis in a positive way at all. In fact almost all of the actions the US government has taken are detrimental to gays and people of colour, as well as to people living with AIDS. Recently, they have gone so far as to bar from entry Canadians going there to buy AIDS treatments that are unavailable here.

In Great Britain, the Thatcher government has continued its war on its opponents with the recently adopted Clause 28, which bans funding for anything that will present gays and lesbians in a positive light. Thatcher, who believes she is winning the war and creating a new "leaner" (read "meaner") society will be once again bringing her influence to bear on Reagan and Mulroney.

We then marched from the 519 to Queen's Park where we joined with the other groups who enthusiastically welcomed us and wore our stickers saying "SILENCE = DEATH". Chuck Grochmal of AAN! addressed the rally describing himself as an AIDS survivor and he drove home the point that the government was criminally negligent in choosing its priorities -- defense and summits before AIDS research.

One of the most important things to come out of AIDS ACTION NOW!"s involvement in the day was the support we received from and were able to give to other groups that are fighting for justice.

Patrick Barnholden
Vive la vie! Agissons aujourd’hui!

Importance des politiques de traitement

Les questions de prévention, avec celles de la transmission, du dépistage et de la quarantaine, relèvent de ce qu’on peut appeler les politiques de protection de la santé. D’autre part, les soins aux personnes atteintes de sida dispensés par les centres hospitaliers et les hospices relèvent de politiques de médication palliative. Il reste cependant à considérer les politiques de traitement. Les questions qui entrent dans cette catégorie sont la qualité des soins reçus dans les cliniques et les centres hospitaliers (de compétence provinciale) et les traitements des personnes atteintes et de celles qui sont séropositives, l’expérimentation et l’éthique sur des procédures comme l’usage de placebos (de compétence fédérale).

Le groupe d’action SIDA-AGISONS AUJOURD’HUI/AIDS ACTION NOW! (AAN!) fait pression sur les gouvernements pour contester l’inaction. Les buts de ce groupe d’action sont l’amélioration des soins de santé et un meilleur accès aux traitements pour le sida. Cette lutte vise l’amélioration et le prolongement de la vie des Canadiennes et des Canadiens atteints du sida ou des affections reliées au sida ou qui sont séropositifs (qui ont été exposés au virus VIH).

Composition du groupe d’action sida

AAN! est composé de cinq comités de travail, qui sont :
(1) La recherche et le développement [actuellement responsable du projet Pentamidine, qui renseigne et rend disponible la pentamidine en aérosol aux médecins torontois et à leurs patients; ce médicament est utilisé dans la prévention de la pneumonie à Pneumocystis Carinii, dont est affligée une grande proportion des personnes atteintes du sida];
(2) L’action publique [responsable de l’organisation des manifestations];
(3) Le lobbying [responsable des contacts avec les politicien-ne-s fédéraux, provinciaux et municipaux];
(4) Les finances [responsable de la levée de fonds pour assurer principalement la production de matériel écrit, la location de locaux de réunion et des envois postaux];
(5) Les médias [responsable de la préparation des communiqués, du bulletin d’information, des conférences de presse et des contacts avec les médias].

Actions concrètes

Le 25 mars a eu lieu une manifestation et procession à la chandelle regroupant plus de 500 personnes qui protestaient contre l’utilisation des placebos dans un projet de recherche étudiant la pentamidine en aérosol. Dans cette recherche, qui impliquerait 300 personnes atteintes venant de Vancouver, Toronto et Montréal, la moitié recevrait un placebo — c’est-à-dire une substance neutre sans effet — à la place du vrai médicament, jugé efficace dans des études américaines. La conséquence d’une telle procédure ferait que quelques-uns des participants à qui on aurait administré le placebo en mourraient et plusieurs autres deviendraient très malades. Il faut voir les questions éthiques qui entrent en jeu dans l’utilisation de placebos dans des cas de vie et de mort comme chez les personnes atteintes de sida. Soulignons d’autre part que la

Commission présidentielle américaine sur le sida a recommandé dans son rapport du 24 février que l’utilisation de placebos dans les essais cliniques soit discontinuée partout où c’est possible parce que, dit le rapport, sans traitement, le sida est une maladie mortelle.

Lors de la première conférence nationale sur le sida tenue à Toronto les 15 au 18 mai derniers, le groupe d’action sida AAN! a manifesté à deux reprises. Lors de l’allocation d’ouverture de l’adjointe ministre fédérale de la Santé, Jake Epp (lui-même absent), les manifestants ont tenu un “die-in” (un “mourra-t-on?”) à l’extérieur du lieu de conférence. À l’intérieur, on a déroulé une bannière sur laquelle on pouvait lire “Epp = DEATH”. S’il n’y avait qu’une trentaine de personnes à 8h30 le lundi matin, on en trouvait près de trois cents lors du “rally” le mardi après-midi. Ce rassemblement recevait l’appui de la Société canadienne du sida (l’organisme regroupant toutes les associations communautaires sur le sida au Canada). Ces initiatives ont clairement fait ressortir dans les médias que le Centre fédéral du sida et le Bureau fédéral de protection de la santé n’ont à toutes fins pratiques rien fait pour la mise sur pied d’initiatives servant à développer et tester de nouveaux traitements pour le sida.

Un délégation s’est rendue à Ottawa le 25 mai pour contester l’inaction du Centre fédéral du sida et faire une démonstration de quatre traitements jugés efficaces mais toujours impossibles à trouver au Canada.

AAN! a aussi participé au Sommet populaire du 19 juin pour réclamer une reconnaissance internationale des essais de nouveaux traitements pour le sida ainsi qu’une coordination internationale de la recherche.

Bernard Courte

[ ] Yes! I’d like to help out!

When it comes to: I Have:

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[ ] I CAN BILLET AN OUT OF TOWN VISITOR

Other:
AIDS ACTION NEWS! June 1988

AAN! Thanks Its Patrons

The printing of this newsletter was made possible in part through funds donated by the following establishments:

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THE DANCE

LESBIAN AND GAY PRIDE DAY

SUNDAY, JUNE 26TH
FIVE P.M. - MIDNIGHT

AT THE DIAMOND
410 SHERBOURNE STREET

ORGANIZED BY
TRILLIUM MONARCHIST SOCIETY
WITH THE
LESBIAN AND GAY PRIDE DAY COMMITTEE

PROCEEDS TO GO TO THE
LGPD COMMITTEE
AND TO
AIDS ACTION NOW!

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[ ] Lobbying Committee
[ ] Fundraising Events Committee
[ ] Public Action Committee
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AIDS ACTION NOW!
Box 325
253 College Street
Toronto, Ontario
M5T 1R5

OR CALL (416) 967-7590
TO GIVE US THIS INFORMATION
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In Memoriam
Alan Dewar (1944 - 1988)

Alan Dewar died on October 4th after a long struggle with HIV illness. He is remembered fondly by his lover James, his family, his many friends and associates.

Throughout the past year Alan had become extensively involved with AIDS ACTION NOW! His personal struggle was ours: to improve the treatment options for people with HIV illness in Canada. Forced to take an early retirement from a distinguished career first in public office as alderman for the city of Oshawa and later as a senior civil servant for the Government of Ontario, Alan re-emerged as another kind of public figure. He represented in the public eye a new attitude to HIV illness, one of positive action and the courage to battle the odds. He gained important media attention by openly going to the US to buy the drugs that would prolong his life. As a result, he helped AIDS ACTION NOW! change the public awareness of AIDS issues and spotlight government inaction in a poignant, effective way.

Alan gave freely of his time, his failing energy and his invaluable experience to help AIDS ACTION NOW! through the difficult, beginning stages of the organization. Through his efforts the Community Initiative for AIDS Research was set up as a charitable wing of AIDS ACTION NOW!, one that will eventually sponsor community oriented, Canadian based treatment research. In addition to a demanding intelligence, a shrewd political sense and a genius for management, Alan also contributed his wit, his humour, his many stories and his elegant home to help brighten the hard work and the long meetings.

Alan’s death brings great loss to his lover, his family, his longtime friends and colleagues, to those who worked with him on AIDS issues and whose work continues. 

Russell Armstrong
In a strong address, he called on governments and the medical profession to recognize the "catastrophic rights" of patients who are in life-threatening circumstances, and to take immediate action to streamline the implementation of new drugs and treatments.

David Adkin

ANNUAL REPORT

Where We Came From:

Last February 4th, more than three hundred people gathered in Jarvis Collegiate to express our anger at what was happening to People Living With AIDS (PLWAs) in Toronto. Most of us were gay men who had personally been touched by the epidemic, either through loss of friends, caring for those who were ill or by finding ourselves ill or HIV positive.

Testimonials at that meeting exposed widespread Federal, Provincial and medical mismanagement of the AIDS crisis, especially in the area of treatment and care. The meeting founded a new organization, AIDS ACTION NOW! and established three major demands of the government:

- Immediate availability of aerosolized pentamidine to PLWAs as a prophylaxis (preventative) against PCP pneumonia.
- A consensus conference of medical personnel and PLWAs to establish standards and coordination of care.
- Government action to make available experimental treatments which were prolonging the lives of PLWAs in other countries and adequate funding to make Canada a leader in AIDS research.

What We Did:

March 25—We organized a demonstration protesting the use of placebos in the announced trial of aerosolized pentamidine, an experiment which put the lives of half of those in the trial at risk for contracting PCP, the major killer of PLWAs.

In April—we set up the Pentamidine Project to help PLWAs who wished to obtain pentamidine in Buffalo to do so and to use it under proper medical supervision. The first issue of AIDS ACTION NEWS! was published.

May 10—We organized the first conference of HIV-physicians at Hart House, U of T, to share information and to learn about the networks in Toronto, of social service agencies and care-giving groups.

May 18—AAN! activists staged a die-in outside the National AIDS Conference in Toronto. Inside others unveiled a banner "EPP = DEATH." AAN! organized a demonstration at the close of the conference which attracted a majority of community-based participants. The burning of Health Minister Jake Epp at that demonstration became an international news story.

May 25—A press conference was organized at the national press gallery in Ottawa, exposing government inaction and three experimental treatments widely used in other parts of the world were publicly consumed on Parliament Hill.

In early June—AAN!'s lobbying committee met with Bob Rae and NDP provincial health critic, David Reville, to voice concerns and to educate the opposition at Queen's Park about the AIDS crisis.

Also in June—Representatives of AAN!, ACT and the PWA Foundation met with the Provincial Minister of Health Elior Caplan to demand a consensus conference be organized.

June 19—AAN! organized a contingent in the Popular Summit demonstrations demanding international co-ordination of AIDS research and AAN! member, PLWA Chuck Grochmal, addressed a rally of several thousand protestors.

June 26—AAN! distributed thousands of copies of "Treatment AIDS" at Lesbian and Gay Pride Day in Toronto and across the country. The pamphlet outlined a list of treatments under testing in many countries, most of which are still unavailable in Canada because of government red tape. The second issue of AIDS ACTION NEWS! was published.

July 5—Representatives from AAN! met with Provincial Deputy Minister Dr. McMillan and Provincial AIDS Coordinator Evelyn Wallace to press demands that treatments be included in the Provincial AIDS Advisory Committee mandate.

September 15—AAN! held a press conference at Queen's Park, sponsored by the NDP, releasing new information dem-onstrating the unethical nature of the ongoing trial on aerosolized pentamidine and asked the Board of Governors of the University of Toronto (whose ethics committee approved the test) and the College of Physicians and Surgeons to raise their ethical standards.

September 17 and 18—Nathaniel Pier's Visit: On the 17th, Dr. Pier, an AIDS activist and physician from New York, met with HIV physicians in a meeting sponsored by AAN!. Later AAN! sent out Pier's treatment regimes to HIV physicians. Pier explained the importance of treatment of HIV infection before full AIDS develops and spoke about current treatments and testing procedures presently used in the USA, most of which are still unavailable in Canada. (A tape of the lecture is available at the AIDS Resource Centre, located in the ACT offices at 464 Yonge Street.)

What We Won:

- The issue of treatment for HIV+ individuals has been put at the top of the AIDS agenda. The medical establishment and the government has been put on record that the gay community and PLWAs are willing to fight for proper care and treatment.

- After our demands for immediate availability of aerosolized pentamidine, a trial of the treatment was approved in March.

- Protests about the use of placebos in this trial forced the investigators to announce a second arm which allowed those who had already suffered two bouts of PCP to get the treatment without placebo.

- Forty people are now receiving aerosolized pentamidine through AAN!'s Pentamidine Project.

- Continuing protests led to the Johnson report which called for a reduction of the placebo group in the AP experiment.

- After he was burnt in effigy Health Minister Jake Epp hurriedly announced $129 million more for AIDS. Only $45 million, however, was slated for treatment research.

- The Provincial government announced that a consensus conference on care would be held December 1st and 2nd this year in Toronto.

- Epp announced plans for the test- (continued on page 3)
AIDS ACTION NOW!

FINANCIAL STATEMENT - October 3, 1988

**INCOME**

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**BALANCE**  $5,890.78
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AIDS TREATMENT AWARENESS

October 17 to 23 is AIDS AWARENESS WEEK (AAW) in Ontario and AIDS ACTION NOW! is happy to be involved by co-sponsoring with A Space the Angry Initiatives, Defiant Strategies Video Series, curated by John Greyson, to be held October 23 to 28.

The theme for this fifth AAW is “Living with AIDS,” to highlight the fact that every person in Ontario is now living with the effects of AIDS, either directly through infection with HIV or indirectly as family, friends, care-givers, co-workers, policy makers or taxpayers. The ACT AAW Coordination Committee suggested several related themes:

1. the importance of putting a human face on AIDS, to show that many individuals are affected, both directly and indirectly;
2. the need for much wider accessibility to drug treatments and therapies for people living with HIV;
3. the significance of injection drug use as a major mode of transmission of HIV, with the possibility of a second wave of infection unless preventive education campaigns and drug treatment facilities are expanded;
4. the continuing need for secure funding to support education and support services over the long term;
5. recognition of the early role that gay/lesbian communities throughout the province have played in confronting AIDS, as others now join the struggle.

AIDS ACTION NOW! is proud to be involved with this project, which will help raise the awareness of all Ontarians about the initiatives and strategies needed to defeat AIDS.

LA SENSIBILISATION AUX TRAITEMENTS DU SIDA

La période du 17 au 23 octobre 1988 a été déclarée Semaine de sensibilisation au sida (SSS) en Ontario. Le thème de la 5e SSS est Vivre avec le sida; on veut ainsi mettre l'emphasis sur le fait que nous sommes tous et toutes touchés par les effets du syndrome d'immunodéficience acquise (sida), soit directement par infection du virus immunodéficitaire humain (VIH) ou indirectement comme membres de famille, ami-e-s, travailleurs, travailleuses dans le domaine de la santé, collègues de travail ou contribuables.

Les sous-thèmes retenus pour les activités de la semaine sont:
1) l'importance de l'aspect humain du sida, une maladie qui affecte plusieurs, directement ou indirectement;
2) le besoin d'un plus grand accès aux traitements et aux thérapies pour les personnes touchées par le VIH;
3) l'importance de l'usage de drogues intraveineuses dans la transmission du VIH, avec la possibilité d'une deuxième vague d'infection si on ne procède pas à des campagnes d'éducation préventive et à l'étendue des maisons de désintoxication;
4) le besoin à long terme pour des fonds en éducation et services d'appui;
5) la reconnaissance du rôle d'avant-garde joué par les communautés gaies et lesbiennes de la province dans la lutte contre le sida, maintenant que d'autres groupes se joignent à elles.

Le groupe d'action SIDA-AGISSONS AUJOURD'HUI/AIDS ACTION NOW! est heureux de s'impliquer dans les activités de la semaine en coparrainant la série de vidéos Angry Initiatives, Defiant Strategies (Stratégies défiantes et Initiatives en colère) et ainsi aider à sensibiliser tous les Ontariens aux initiatives et stratégies nécessaires pour vaincre le sida.

Bernard Courte

Tim McCaskell
AIDS ACTION NOW! Policy Paper
Adopted by the General Meeting Held October 5, 1988

Advances in the fight against AIDS have brought us to the point where we can begin to look at AIDS as a chronic illness rather than a universally fatal disease. Unfortunately, we are still faced with a variety of problems that prevent us from adequately dealing with it as such. AIDS ACTION NOW! has come up with seven main policies that would make treating AIDS as a chronic illness a reality. We list them here and plan to fight for their adoption in the year to come.

CATASTROPHIC RIGHTS

People Living with AIDS and others in catastrophic life-threatening situations have an unrestricted right to treatments which they and their physicians believe to be beneficial. This includes access to and availability of all drugs and treatments that can be used to treat HIV-positive people and people living with AIDS. These drugs should be available free of charge even when they have not been given government approval for regular distribution. People in life-threatening situations do not need to have their treatments hampered by government bureaucracies or medical researchers who work within the government’s restrictive regulations. The policies that they have in place are clearly designed for situations that are not life-threatening.

When people discover that they are HIV-positive they are faced with many decisions regarding their health care. These decisions, which can be life and death decisions, are now made in a situation that does not allow for the full range of treatment possibilities. Our government continues to deny us treatments that have proven successful elsewhere and, in collusion with the pharmaceutical industry, is inflicting unethical placebo testing on Canadians in life-threatening situations.

DRUG TRIALS AND PLACEbos

Placebos have no place in the treatment of people living with AIDS. People in life-threatening situations should not have to put their lives in jeopardy by receiving no treatment at all. As it stands now, multinational pharmaceutical compa-

nies, in conjunction with governments and medical professionals, are engaging in and promoting placebo-controlled tests. These tests stipulate that a portion of the test group (usually one-half) will receive the drug being tested and the other portion will receive a placebo—a practice that means one-half will receive something that is designed to look like medication but is in fact a substance with no medicinal qualities at all.

AIDS ACTION NOW! supports full testing of drugs—with the stipulation that they should still be available in “catastrophic” situations even while undergoing testing and that the tests should be done only using either historical or comparative controls where different dosages or other drugs are administered.

ANONYMOUS TESTING

All levels of government should be working together to provide sites for anonymous testing in Canada. At present seven Canadian provinces require the reporting of HIV positive people to authorities. These requirements should be altered so people can have the tests anonymously - that is to say by being able to receive their results without the people giving them the results being required to report their status to provincial medical authorities. Anonymity should be guaranteed when wanted and at all times people should be able to expect complete confidentiality of their medical records. People should have the right to know their health status without fear that their condition will be reported to the authorities or perhaps leaked to their employer or elsewhere.

PLWA’s ON ALL BOARDS AND COMMITTEES

Boards and committees that are dealing with the health and lives of people living with AIDS should always have PLWA’s as members. This should include any body that is dealing with any aspect of AIDS - issues such as hospital care, home care, human rights or education about AIDS can only be adequately dealt with through the full involvement of PLWA’s. Prerequisites for the full participation of PLWA’s are anti-discrimination legislation and the guarantee of no quarantine legislation.

NATIONAL TREATMENT REGISTRY

A national treatment registry should be established. Such a registry will be composed of a variety of treatment protocols thought to be of use to people living with AIDS or HIV infection. Primary-care physicians would access this registry with inquiries for treatment protocols to suit the individual needs of their patients. Reports to the registry of individuals’ treatments and health status would be made on a continual basis. Treatments of all types, including those that are not part of the medical mainstream, would be recorded. Both physicians and PLWA’s should have access to the information in the registry so that PLWA’s can be active participants in their own treatment. This registry should be established and run by a body that includes the full participation of PLWA’s.

The national treatment registry will be a very important tool in bringing together the existing knowledge about AIDS and the ever-widening scope of treatment options. It is important that the registry be connected with other such registries in other countries. This will also allow the treatment of PLWA’s and HIV-positive people to move away from a strictly hospital setting and more into the home and primary physician’s office.

HOSPITAL CARE

Hospital administrations must work much harder at establishing state-of-the-art diagnostic and treatment protocols to deal with the health of PLWA’s. At present there is no uniformity in care available for PLWA’s in different hospital settings. PLWA’s are continuing to have horrific experiences as they deal with hospitals where a “hit and miss” approach governs present attempts at AIDS care.

It is the responsibility of the provincial Ministry of Health to establish standard protocols for all hospitals so that care can be brought up to an acceptable level.
AIDS ACTION NOW! Annual General Meeting

AIDS ACTION NOW! held its first annual general meeting on October 5th, with about 75 people attending at Toronto's 519 Church St. community centre. Items on the agenda included a report on progress (see p. 2); a seven-point program for policy direction (see p. 4) and the election of a new steering committee.

The meeting opened with greetings from organizations doing different kinds of work around AIDS issues. Art Wood, the chair of the AIDS Committee of Toronto, brought congratulations for the political work that AAN! does and said the he sees the work our two groups do as "complementary." Jeff Braff, the newly elected Chair of the Board of Directors of the Canadian AIDS Society/Société canadienne du sida, gave a short history of the CAS stressing that it sees its role as providing "strength of unity without taking away from the autonomy of individual community groups" that make up the CAS (of which AAN! is a member). Pointing out that AAN! demonstrations show that "activism equals life," Braff said that we had a real effect on the federal government. Jake Epp's recent announcement that he was setting up a working group to look at AIDS issues is, according to insiders, a direct result of heat resulting from AAN!'s earlier actions—including our burning of the minister in effigy. This working group, with Braff as one of its members, will be reporting directly to the minister and will not, in Braff's words, "be a whitewash."

George Smith then gave a talk stressing that AAN!'s most important task is to focus on treatment and that this means early intervention. Said Smith: "You get AIDS when you become infected with HIV. Early intervention improves results."

Things that AAN! has to do in the immediate future include (1) organizing around the consensus conference in December, (2) dealing with the federal election in which all three parties have agreed that AIDS should not become an issue and (3) waging a public campaign against the use of placebos in the recently announced trials of five AIDS treatments.

An important part of the meeting was the point at which we heard some stories of the terrible care and treatment that people living with AIDS are continuing to receive. Ned Lyttleton, a counsellor with ACT's AIDS Support, said that "PLWAs are treated in hospitals as if they were already dead." Although he hears some good stories about care people receive, Lyttleton says that there is no hospital with a universally good reputation. PLWAs face constant "subtle and not-so-subtle homophobia," he said. Chuck Grochmal then described a new watchdog Citizens' AIDS Review Committee that has just begun and will be looking into some of the intolerable conditions existing in hospitals.

After adopting the seven-point policy program, the meeting went on to elect a new steering committee. The new executive is composed of Tim McCaskell as chair, Russell Armstrong as secretary, and James McPhee as treasurer. At-large members of the steering committee are: Max Allen, Dennis Conway, Bernard Courte, Renée Duplessis, Chuck Grochmal, Sean Hosein, Michael Hulton, Gary Kinsman, George Smith and Roger Spalding. Each of AAN's five committees (Public Action; Press and Media; Research and Development; Lobbying; and Fundraising Events) will also send a representative to the Steering Committee.

Patrick Barnholden

Pictured above is Tim McCaskell, newly elected Chair of AIDS ACTION NOW! Photo by Chuck Grochmal.
AIDS TREATMENTS MUST BE AN ELECTION ISSUE!
Where do the parties stand on access to promising new AIDS treatments?
THEIR SILENCE = OUR DEATH
The Tory government has buried promising AIDS treatments under mountains of red tape — their record is four years of neglect.
The other parties remain largely silent...
MAKE AIDS ACTION AN ELECTION ISSUE!
END THE SILENCE!

RALLY, MARCH, ROAST
SATURDAY, OCTOBER 22, 7:30 P.M.
STARTING AT: 519 CHURCH STREET COMMUNITY CENTRE, TORONTO

WOULD YOU LIKE TO BE ON OUR MAILING LIST?
IF SO, SEND THE COMPLETED FORM BELOW TO:

AIDS ACTION NOW!
BOX 325 — 253 COLLEGE STREET
TORONTO, ONTARIO M5T 1R5

[ ] Yes! I’d like to be kept abreast of things.
Name: ____________________________ 
Circle One: Mr. Ms. Dr. Prof. Rev. 
Address: __________________________
Postal Code: ______________________ 
Phone: ____________________________

Policy: This information will be used only to contact you.
Our mailings will be in plain envelopes.

I own or have access to: 
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[ ] Video Recorder [ ] Video Camera [ ] Public Address System
[ ] Other: __________________________

I would especially like to help out: 
[ ] Press and Media Committee
[ ] Lobbying Committee
[ ] Fundraising Events Committee
[ ] Public Action Committee
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Monday, October 24, 7:30 pm
MORE PLEASURE/DANGER: WOMEN AND AIDS

Tuesday, October 25, 7:30 pm
AIDS AND THE LATIN AMERICAN COMMUNITY

Wednesday, October 26, 7:30 pm
SEX, PORN AND AIDS

Thursday, October 27, 7:30 pm
AIDS AND THE BLACK COMMUNITY

Friday, October 28, 7:30 pm
AIDS ACTIVISM

A BENEFIT FOR AIDS ACTION NOW!

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